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Living Profiles: Design of a health media platform for teens with special healthcare needs

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ABSTRACT

Living Profiles is a health media platform in development that aggregates multiple data flows to help teens with special healthcare needs (SHCN), particularly with regard to self-management and independence. A teen-oriented personal health record (PHR) incorporates typical teen behaviors and attitudes about health and wellness, encompasses how teens perceive and convey quality of life, and aligns with data related to their chronic medical condition. We have conceived a secure personalized user interface called the Quality of Life Timeline, which will assist with the transition from pediatric care to an adult provider through modules that include a mood meter, reminder device, and teleport medicine. With this personalized PHR, teens with SHCN can better understand their condition and its effects on daily activities and life goals and vice versa; additionally, use of this PHR allows for better information sharing and communication between providers and patients. The use of a teen-oriented tool such as Living Profiles can impact teens' overall quality of life and disease self-management, important attributes for a successful transition program.

1. Project goals

In 2006, as part of *Project HealthDesign*, a national initiative funded by The Robert Wood Johnson Foundation, a multi-disciplinary team of designers, health providers, engineers, and teen participants embarked on creating a personal health record (PHR) oriented towards teens with special healthcare needs (SHCN). Through an iterative design research process which focused on the assessment and incorporation of teen ideals and sensibilities about health and wellness, the team created a prototype personal health record, Living Profiles [1].

The main goals of Living Profiles are to address the needs of teens with SHCN and to assist in transition – defined as the planned, purposeful movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems. The goal of transition is to provide care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive [2,3]. Many transition programs focus primarily on the service transitions and transfers of care without integrating information technology into the process [4]. As online media such as webpages, blogs, and social networking sites have become integral in teen self-identity and expression of social development and emotion [5,6], use of these modalities in health and well-being management is warranted, especially in providing a holistic and individualized transition process.

Based on pre-design research using cultural probes [7] and dyad in-home interviews, we found that teens with SHCN do not necessarily associate their sense of personal identity with their condition, but rather through social and peer interactions and emotional states. Without a solid connection between self-awareness and health, teens' perceptions of well-being and positive self-esteem can be stunted, limiting the transition process and it potential success [4,8,9]. Technology can facilitate these behaviors, exemplified by the ubiquitous activities of text messaging and accessing social media sites as modes of self-identity expression and communication

Abbreviations: PHR, personal health record; EMR, electronic medical record; SHCN, special healthcare needs; QLT, Quality of Life Timeline.

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[10,11]. Given the complexity of teen self-identity formation, multiple inputs, ranging from web-based browsers to mobile technologies such as cell phones, are required for a teen-oriented health management tool that can assist in the transition process by promoting independence and self-care. From a design standpoint, a teen PHR needs to reflect their individuality and perceived quality of life, and allows for information sharing with others such as a provider, family member or friend; in order to increase the potential for adoption by the user, it must align and integrate with typical behaviors. Additionally, personal control over the information is paramount, as are the PHR's capabilities to maintain privacy and security.

2. Quality of Life Timeline

The primary design concept proposed for Living Profiles is a health media platform that allows for the secure aggregation of multiple data flows including images, texts, video, blogging, and data acquired from activities of daily living such as medication tracking. The Quality of Life Timeline (QLT) is a web-based user interface within this health media platform that presents these aggregated data in a unique, personalized calendar format. Through the *Project HealthDesign* initiative [12], a common platform was available for the QLT to store and access data, as well as to structure log-in capabilities with different devices (e.g. mobile phones or personal computer) and applications, including an authentication and authorization system.

Within the QLT, we propose a host of modules that capture various observations of daily living such as mood, reminders (such as for school assignments or medication intake), or real time health events – all of which are integrated into routine teen behaviors. Our three initial modules, which can be stand-alone applications, are a mood meter, reminder device, and a teleport medicine module. To contextualize the information gathered from these modules and to foster the adoption and use of the QLT, teens populate the UI with items such as pictures, videos, and music gathered from their mobile phone or other devices that can provide insights about teen self-identity, discovered through the cultural probe activities originally created for our pre-design research process. The UI includes an area to document short- and long-term goals; current media trends that may evoke emotional or psychological clues about their health and wellness state; and an ability to annotate and comment on current and past events. Data are collected from technologies used in teens' everyday lives without necessarily impinging on normal routines.

This PHR tool provides for teens a vehicle for better self-management and communication about health, important skills necessary for a successful transition. Conceptually, through the QLT teens with SHCN collect information that they deem important to their quality of life to review later, self-reflect and possibly share with their providers. In so doing, teens may gain insights about their medical condition and its impact on their health by aligning these items with more personal and experiential observations. The QLT provides a venue to post questions about their condition to be used at home, school, or in clinic and can be adapted to link to websites that may provide educational resources or support networks. Providers have a window to assess potential changes or problems by viewing observations of daily living (mood alteration, stressors with upcoming events or goals) and supporting that information with medical data (e.g. signs of anemia or inflammation from laboratory work), which can open up an opportunity for both teen and provider to discuss these findings and their effect on a teen's quality of life. The providers also can leave notes and recommendations within the QLT that teens can review.

Extensive patient testing using design research methods helped to define the Living Profiles concept. Prior to creating a functional prototype, we tested the health media platform concept by showing teen participants a video scenario of a user's experience with Living Profiles and assessed teens' responses. Overall, teen participants identified with the ability to control and share daily experiences with their providers and agreed that collecting these data should require minimal input. Concerns raised about the user experience were more practical in nature, focused on costs and the integration of the tool with their own phones and calling plans. Privacy was also questioned, primarily related to the realities and logistics of sharing the collected QLT information with their healthcare providers – as well as wondering if their providers would care about this information.

2.1. The mood meter – example of the QLT functionality

While the proposed QLT will collect many data elements, we have concentrated on developing our initial module that best embodies teen behavior and self-identity formation – the mood meter. Being able to interpret and understand the emotional fluctuations of a teenager can be extremely useful for teens, friends, families, and providers to view its impact on health and wellness. Currently the mood meter is the only functional QLT module and derives its data from outgoing text messages from a teen's mobile phone. The mood meter parses text messages into individual words, representing word frequency in a landscape of hills and valleys, and randomly highlighting a texted word in an ever-changing word cloud using Flash – all done without a change in a teen's typical behavior (e.g. sending text messages) and seamlessly integrated into the phone's operating system. By providing access to this information in a compelling and novel way, the teen can gain insight about their mood, emotional and/or physical states.

Preliminary analysis derived from user testing of the mood meter module shows that teens find text messaging a compelling way to evaluate mood and interpret stressors in their lives, which can potentially be a point of conversation between a teen and provider. The following transcript describes one teen's reaction while reviewing the mood meter's word cloud feature:

> *Interviewer: [P]ick a word that might come out. Does it remind you of anything?*
> Teen: Physics, that's usually a stressful word... that comes up a lot... when I talk about Physics it means that I'm really, really angry at it. I'm just like "Argh, I don't like Physics" or "Did you do the physics homework?"
> *Interviewer: So it's interesting-... it's right around noon.*
> Teen: That's when I'm in Physics! People are like, "What class are you in?" and I say, "Physics!"... That's funny, because that's right where physics is (points to noon). I guess that one helps. Wow, I say it lots.
> *Interviewer: Physics obviously causes you angst.*
> Teen: Yeah, it really is! I just got a test back that dropped my grade 15%.

Teen participants are interested in delving deeper into the mood meter, promoting the additional functionalities for searching and aggregating words/times/moods, and are interested in its potential in better understanding their overall health state through interpreting their routine behaviors and attitudes. Another option we plan to add is sending a text prompt for teens to document their general mood for a day or specific time period via their mobile phone so as to provide a context for the variations in the mood meter display.

The mood meter module demonstrates the complex structural architecture required for the QLT in the proposed health media platform:

- Text messages from the mobile phone are automatically uploaded to the server by a program pre-loaded onto the phone's operating system before deployment for teen use, and the user is recognized through a log-in protocol with an authorization and authentication process allowing for security and privacy;
- The server is secure, and the database allows for storage of information based on date and time of message allowing for viewing of simultaneous QLT events, as well as the potential accessibility for other devices or application;
- Outgoing message data are presented within the QLT user interface using Flash to provide a dynamic visual output; and
- The mood meter UI allows interactivity and personalization in interpretation, when viewed in conjunction with other modules and elements of the QLT.

The architecture for this health media platform is seen in Fig. 1.

2.2. Other QLT functionalities

In addition to the mood meter module, the other currently developed functional components are the QLT user interface design created in HTML and the basic architecture for data storage and access, including the log-in process with user authentication and

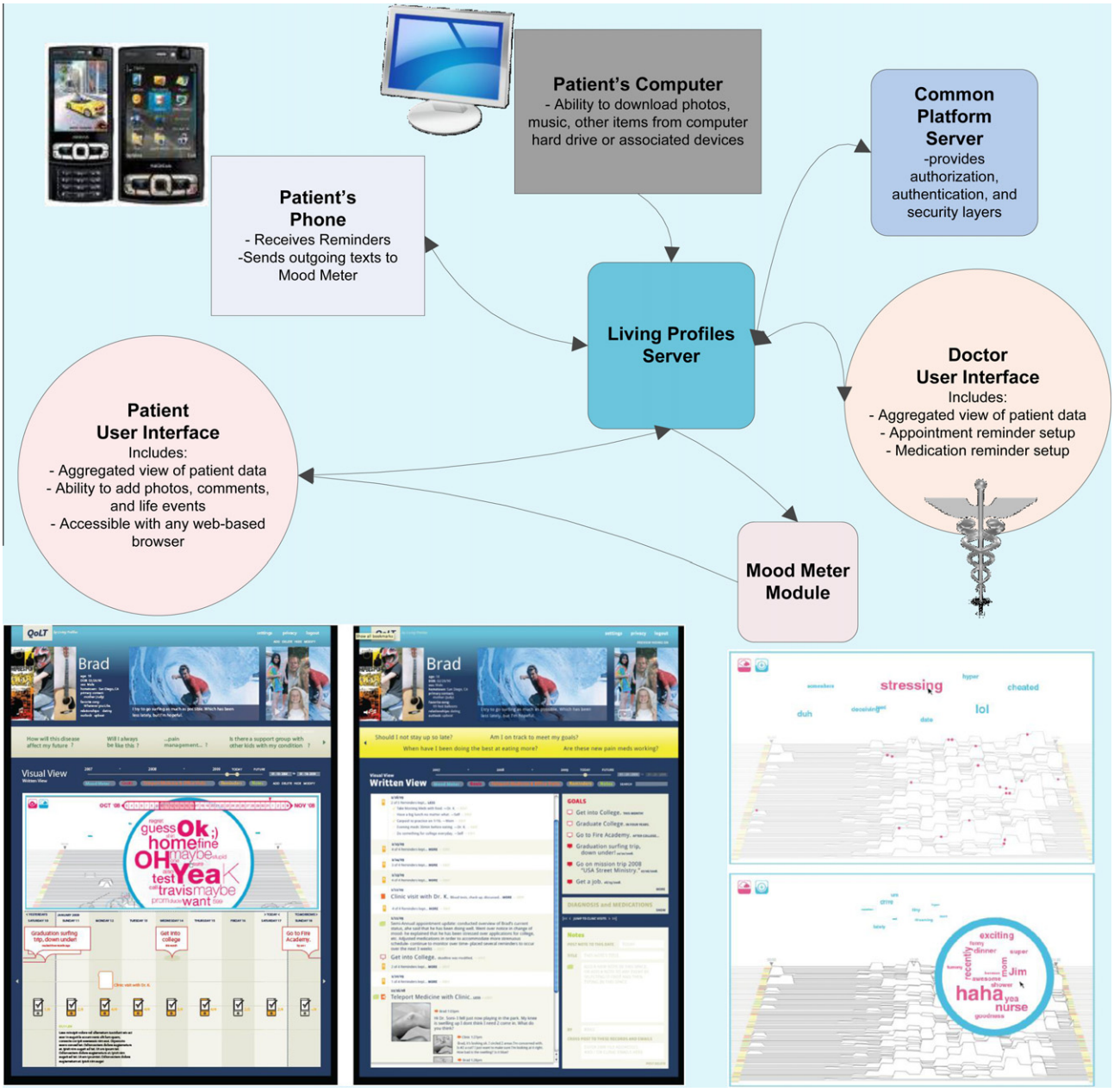

Fig. 1. Living Profiles Health Media Platform is a dynamic system that multimedia inputs provide functionality and personalization to the user interface used by both patient and provider. The Quality of Life Timeline (shown here with its two formats) aggregates information and data derived from home computers, mobile phones, and potentially other devices that get stored in the Common Platform server. Currently, the mood meter module is functional allowing for two methods of viewing (top is the "word cloud" in which a random word is selected and can be highlighted to view word frequency, bottom is magnifier view showing the 30 most frequently texted words for a day ± 3 days). Living Profiles can be a powerful tool to track health and wellness, opening new opportunities for patient-provider interactions and improved self-identity formation and expression, important for a successful transition.

authorization, provided through the *Project HealthDesign* common platform. The system has been presented to teens with SHCN to assess their responses and attitudes. Teens are drawn to the UI and its content. They feel that the items placed in the QLT and the persona portrayed in this format is far more reflective of their individuality than the persona a health provider typically generates during a clinic visit. Notably, they want the capability to alter the QLT periodically to ensure that the personalization stays current and is reflective of their identity at that particular moment (data shown to teens came from cultural probe activities 2 years prior). Teens also express that they would share the QLT not only with their healthcare providers but also with friends and family. They note that they would want to see how their friends would fill out the QLT, even if they do not have a medical condition, demonstrating how the elements within the QLT contain universal traits for teen self-identity formation and expression.

3. Discussion and implications

Through *Project HealthDesign* and Living Profiles, we have brought to light the opportunities in the design, development, and evaluation of a PHR oriented for teens with SHCN. Our model introduces a broader concept of a health media platform. While we currently have structured Living Profiles onto a single entity common platform to store and access data from our QLT, we foresee fluidity in the data flows and interactivity with various datasets found on multiple servers. Our QLT user interface can restructure these data into a usable, shareable format that allows for personalization using different media.

Our focus for this project was increasing the usability and potentially functionality of a teen-oriented PHR, based on the patient users. Our mood meter module and design of the QLT are currently functional, and user testing with teens demonstrates their potential utility for teen health awareness. We understand that PHRs will require extensive work with regard to interoperability with different operating systems (including EMRs and social networking sites). Another issue is assessing providers' use and acceptance into clinical work flows as both of these items may reduce the impact of Living Profiles if it cannot be integrated into clinical practice. Additionally we acknowledge the challenges of privacy and confidentiality of PHRs, exacerbated by our teen population and the limits of their legal rights when it comes to health information – *Project HealthDesign* provided the Ethical, Legal, Social Implications group to raise awareness of the need for further research surrounding these issues, especially with regard to provider responsibility if teens disclose risky or life threatening behaviors within Living Profiles [13].

Despite these various barriers, getting teens with SHCN to be more involved with their health and wellness management will have beneficial consequences and merits further work and evaluation of integrating technology into this process. Successful transition care requires good patient-provider communication, independence, and self-management to navigate the world of adult medicine. Investment in interventions such as Living Profiles and continued development of the health media platform concept are warranted.

4. Overview of implications

Living Profiles introduces the concept of a health media platform as a method to integrate multiple tools and devices to assist with health and wellness management and the transition from pediatric to adult medical care for teens with SHCN. Specifically, it is a teen-oriented personalized user interface called the Quality of Life Timeline that helps to organize and present multimedia, health and medical information in a functional user-designed format based on teen routine behaviors.

Conflict of interests

Lisa Nugent is an employee of Johnson and Johnson Corporation, New York, NY. The other authors declare no conflicts of interest.

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